Beyond the Surgery

General practitioner in a hospice

ERIC WILKES

Being in a country practice, the general practitioners in my group were among the fortunate minority who had direct access to a tiny cottage hospital: and there, among the patients with bad backs, bad chests, and stroke, quite a few of our patients were admitted to die. It could not have been a less frightening admission for them, coming into the small traditional building with its marble war memorial and the faded wreath of poppies in the front porch. The patients were among their own people. I remember asking a ward sister why she was herself feeding a local teacher as he was dying drowsily from his astrocytoma. Rather indignant that the question was being asked, she replied, "He taught me French." Relatives drifted in and out. The food was good. The hospital was so expensive to run that the regional board wanted to close it down, but they did not relish a confrontation with an indomitable local solicitor and the Royal British Legion.

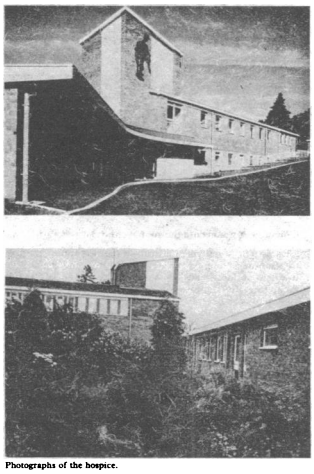
It was an obvious step to wonder how they were getting on in Sheffield, half an hour away. They had as much capacity to care as we had and a great deal more clinical skill, but they had no cottage hospital for their dying patients. With help from Sheffield colleagues I did a survey and found that according to their general practitioners most terminal patients did not suffer too much, but that 12% needed a hospital standard of nursing care and their Sheffield GPs could not get them admitted.

This was all 15 years ago. They were just thinking of opening St Christopher's Hospice, and there was no similar unit anywhere in the provinces. The regional hospital board agreed that such a unit was needed but said that they could not possibly afford to build it. They did agree, however, that if we raised the money to build from private sources they would help generously with the running costs. Of course, they would not promise this now. Even then, I suspect, they agreed only because they thought we would never raise the money; or perhaps they were rather impressed by the small group of doctors and prominent citizens with whom they were dealing: for now we had formed a steering committee to get things moving.

Starting from scratch

The dreary business of fund raising began. Quickly I learned that the medical practitioner still has influence, even on a frightening scale. One of my most difficult patients, when I asked for help, said at once, "Here is a cheque for a thousand pounds. I do not want to know any details. If you need it, that is good enough for me." Others were even more generous. Highly respected colleagues joined us. The secretary to the project was an incredibly efficient girl. Without their help we could never have succeeded. We gave ourselves 18 months to raise our £120 000. We just made it, but it nearly killed me, for I was still in full-time general practice.

Next the steering committee had to find a site, choose an architect, and plan the building in detail. The local roots again helped out, and the British Steel Corporation gave us a fine two-and-a-half acre site with minimal safeguards to protect their interests. We used the architect of St Christopher's Hospice. They found us hard to deal with for we had high-quality planners, doctors, nurses, and businessmen on our building committee. We knew exactly what we wanted but did not really want to pay for it. Eventually we got a heart-warming,



Photographs of the hospice.

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attractive, efficient building. Only the design of the kitchen was overprofessional and less than good, but even here we have learned not only to live with it but to produce very good food as a routine.

Then, as the roof went on, we began to recruit our staff. The first three appointments were the matron (wisely we kept the old nomenclature), the volunteer supervisor, and the head cleaner. It just happened that they were all very good appointments. I had slightly known the matron years before. She proved a creative leader who made an enduring mark on our standards of care. We employed her for six full months before we opened, and this was one of the best investments we ever made. She recruited, indoctrinated, and trained a mix of nurses returning after years away from their profession, housewives, and volunteers, and she welded them into a fine nursing team. The first matron has retired and her worthy successor is in post, but the original volunteer supervisor is very much still with us, running with quiet authority a department of 300 volunteers who are engaged in every aspect of our work.

The hospice now

We have now been open for nine full, busy years. We are staffed on the medical side by three general practitioners, of whom I am one, plus a senior house officer on the local vocational training scheme. We have a waiting list, as always, of nurses who wish to work with us. We still seek to achieve the highest degree of symptom control and independence for our patients. We still try and treat the relatives as if they were our guests, whether they are shy and inarticulate or, usually with reason, slightly aggressive. It has worked out amazingly well, despite our inevitable difficulties and failures.

Success has brought its own problems. We can expect, for example, to admit nearly 400 patients each year from some 200 general practitioners, but we still have 150 patients for whom we cannot find a bed and who die on our waiting list. To help here the Nuffield Foundation generously helped to build our special day hospital that supports families as well as patients and is arousing interest in several countries. Our teaching and rehabilitation commitments have grown so much that we expect to open our extension to help cope with this early next year. This we expect will be our last major development on a site where the building now must have an insurance value of something like £1½ million.

What have I personally learned from all this?

I have learned that duchesses and lord lieutenants and even sardonic general practitioners will help if they believe in what you are trying to do. I have learned of the crucial importance of the physiotherapist and the occupational therapist in transforming the atmosphere of the ward and giving purpose and dignity to the patients' day. I have learned of the vast scale of loneliness and grief caused by bereavement, and how our social workers' bereavement visiting service can be so important when the doctors are slow to realise the extent of the suffering that may or may not present to them.

Perhaps the other perpetual surprise is the humour and courage of our patients. These make the unit such a good place to visit that I go there not to give cheer but to receive it. It is a place of laughter, though this is not irreverent or misplaced. There are, of course, tears, too. The only time I have broken down in my professional career was here. A wasted little old lady blessed me with great dignity minutes before she died. Then I cried, but I don't need to make a habit of it.

Despite great support from the National Health Service we still need £2000 each week to maintain our services. The National Society for Cancer Relief has helped so much by funding our community nursing service, but money is naturally a recurrent anxiety. We think that it is a good thing that most of this support comes from local sources. It reassures us that we are thought worth it.

The university may have regretted on occasion its agreement that I would continue to work here, but it has never said so. This commitment obviously has used up some of my time and energy, especially as the teaching load has grown. My role has changed gradually over the years. Nowadays problems are more hidden from me than brought for solution; nor do I quite know when I should resign. The unit does not need me much now, but it has been one of the most fulfilling and inspiring activities in a life that could otherwise be described—perhaps like other general practitioners'—as one of feverish ineffectiveness.

Clinical Curio: home birth

"What are you doing here?" the 4-year-old boy asked me at the door to the caravan. Mummy was in labour with her third baby. Inside, the midwife was watching, bewildered, as she grunted happily through a pain on all fours on the floor. One neighbour was brewing a pot of herbal tea and another reading a fairy story to a little girl. I put the midder bags out of sight in the bedroom. In case anything went wrong, I supposed.

She climbed up on to the sofa to push, and at the first sight of the baby's head the rest of the neighbours were summoned. Chairs were set out for them at the foot of the couch, and I quite expected someone to arrive selling ice-creams and cartons of orangeade. I almost missed the climax. It was all too much for the little boy. He took my hand and led me out to the paddock to admire his donkey. He listened gravely to my explanation that mummy was not crying because she was unhappy; things had to stretch to let the baby out and it was just a bit uncomfortable.

There was absolute silence as the head crowned, followed by a cheerful outbreak of chattering and congratulations as the infant slithered out and gave a yell—the happiest sound in the world. "Apgar," I said to myself, confused by the commotion, but someone was asking me what the time was. The moment of birth, for astrological purposes, was when the cord was cut. The midwife was waiting for the vessels to stop pulsating but mother was impatient—she wanted to hold the baby. At 4.32 pm the little Taurus's last physical link with his mother was severed and a moment later he had stopped bawling and clamped his mouth to the breast.

No drugs, no shaving, no enema, an immaculate perineum, and I eventually got to have a close look at the baby's parts: a beautiful, healthy, 7½ lb boy. I rang the consultant to tell him. "You're lucky," he said grimly. Yes. She had been admitted to hospital on two occasions to be dripped out of premature labour. She had been a "high-risk" mother from the start: a 36 year old wanting to have her baby 30 miles from the nearest obstetric unit in a caravan in the middle of a muddy field. The midwife and I lost the argument, and I am glad, in the end, we did.

The mother came to the clinic for her postnatal and on the way out said to a girl there, due to have her first baby any time: "Have a nice time." It should be, shouldn't it? We hear a lot nowadays about dying with dignity. Couldn't we GPs and obstetricians bury our prejudices and find a way of helping mothers to give birth with dignity? My wife is due to have a baby soon. I hope she has a "nice time," but I don't think I'll be inviting the neighbours in.—A Welsh general practitioner.

We will be pleased to consider for publication other interesting clinical observations made in general practice.—Ed, BMJ.

Patient Participation

What is it?

The words "patient participation" are apt to strike enthusiasm, or sympathy, or apathy, or a real chill in the hearts of general practitioners. Such reactions suggest that the two words are charged with meaning. As the trend now is for consumers to look more critically at the quality of the goods and services they pay for, some GPs may think that patient participation means "patient power" and—taking this to its ridiculous extreme—audit by patients. But there is an important point to be made here about patient participation groups. Of the 30 or so that have sprung up over the past eight or nine years in Britain, nearly all were started at the suggestion of general practitioners, and the few that were initiated by patients did not survive without the support of a GP in the practice. Furthermore, each group functions according to the needs of the practice, and the only pattern that can be discerned among groups is that they all hold meetings.

The National Association for Patient Participation in General Practice, formed in 1978, encourages groups to develop according to the needs and wishes of the patients and doctors (and health staff) in a practice and not according to a model. It confines its role to being a "link" between groups.

Some groups meet to sort out difficulties in the practice organisation—such as surgery hours, picking up repeat prescriptions, child-minding for mothers coming to the surgery. Some have broadened their activities to include voluntary work—driving patients from outlying areas to surgery, keeping a look out for elderly people in the neighbourhood. And some support health education as well, by holding lectures and discussions and making video tapes. The remit is broad. As for how they are organised, some are elected committees, some are made up of representatives appointed by community groups, some are made up of all interested patients and health staff in a practice, and some are combinations of these.

The groups that have been meeting regularly appear to act as a safety valve for resolving the small irritations that crop up in any organisation, whether it is large or small, thus probably forcing the patients and doctors to look at each other's problems with sympathy and understanding. It appears that criticisms of doctors and how they practice medicine are few and far between, and that these groups are not a means for venting spleens.

Doctors who don't know what goes on in a patient participation group and who are curious or wary, or both, may want to read the next few articles on patient participation, which tell what the groups in Berinsfield, Aberdare, Bristol, and Birchfield actually do.—SUE BURKHART, staff editor.

Berinsfield Community Participation Group

JAN BURGESS

The Berinsfield Community Participation Group started in 1972 when the practice moved to a new health centre. The doctors were planning new services and wanted closer communication with patients to discuss planning, opinions, and complaints, and in addition they hoped a patient group would provide a means of transmitting information about health education. Organisations such as parish councils, and women's, old people's, and children's groups in the six villages served by the practice were invited to send a representative to the first meeting in November 1972. The professional health centre staff were also invited, and more recently the receptionists asked to attend and immediately received invitations.

The meetings are held three times a year. There is no formal constitution or committee, but a patient takes the chair to co-ordinate the discussions. A survey done in 1977 showed that of the 130 topics discussed during the previous four and a half years only a third had been raised by patients. During 1980 we discussed 31 topics, 42% raised by patients: a small increase, but still supporting the theory that the doctors contribute to and benefit more from the group.

The group has proved to be a good channel for health education, for the discussion of new training techniques (this is a training practice), and for general comments about the functioning of the health centre. Patients and professionals continue to benefit from a greater understanding of each other's problems. The representatives report back to the village groups that they represent and bring any comments to the next meeting. In some instances the opinions of the lay members are contrary to those of the doctors. The doctors, however, never consider

Berinsfield Health Centre, Oxon
JAN BURGESS, chairman

these opinions as a veto, but rather as a guide how best to consider the patients' feelings, feelings the doctors might otherwise have been unaware of.

Topics discussed at meetings last year

RAISED BY PATIENTS

Is there a suitable time for telephoning one's doctor for advice? The most suitable times were clarified.

Use of voluntary funds to improve community service.

Aims of the group and who it represents . . . 3000 leaflets were distributed to advise more patients of the existence and function of the group. The area health authority provided a grant of £10 to help with the cost.

During an outbreak of gastroenteritis, mothers asked that information on managing the illness be sent to local children's groups and schools.

Some patients prefer to consult a woman doctor . . . a woman doctor is now at the health centre on the day when one of the partnership doctors is away.

The existence and functions of a neighbourhood information centre were explained.

Is there anywhere that mothers can leave small children while they consult their doctor? . . . there are three places. It was also suggested that outlying villages might organise a child-minding scheme.

Patients in the sub-waiting area can hear conversations in the treatment room . . . this cannot be dealt with economically.

One of the car service (a voluntary service for patients from outlying villages) drivers had found delays in picking up repeat prescriptions from the health centre dispensary . . . it was pointed out that 24 hours' notice is required for repeat prescriptions. This is now being given.

It being the International Year of the Disabled, the group sent a letter to support planned long-stay beds for young disabled persons.

The long-sought chiropody clinics have become unreliable . . . the doctors wrote to the area chiropodist.

RAISED BY DOCTORS

The need to redecorate and maintain the health centre . . . the group wrote a letter to the area health authority supporting the doctors' requests. The health centre has since been redecorated.

Prescription charges would be more rigorously collected after discovering a shortfall in those collected during the previous year.

Mothers were requested not to bring sick babies to the well-baby clinics.

A doubling of night visits during the previous four years was discussed . . . and, after a patient's suggestion, it was found that 20% of the visits were to patients who had visited the health centre in the previous 48 hours. During 1980 the "out-of-hours" calls decreased by 25% over 1979. There was a slight increase in calls for advice and help with drunkenness. Consequently some information on basic procedures for dealing with drunken persons was published in the local newsletter.

The procedure for same-day appointments.

The questionnaire for new patients may be extended to cover social factors and screening data.

Saturday morning dispensing is for emergencies only . . . out of dispensary hours the doctors will dispense the medicines prescribed.

The new regulations concerning social security sickness certificates . . . patients could still have a private certificate, but may be charged the fee recommended by the British Medical Association.

New magazines were required in the waiting room . . . there was an immediate response.

The threatened closure of the local hospital's maternity unit . . . in the event it is to be saved with reduced capacity, but more geriatric beds will be available.

The small number of patients needing the treatment room sister during one of the evening surgeries suggested that she need not be present . . . the group recommended a trial period without the sister during that surgery.

The general reduction of patients wishing to consult the treatment room sisters could allow them the time to do preventive medicine, such as screening clinics.

Changes in the doctors' attendance at particular surgery times were mentioned.

Suggestions were invited for health education topics that could be discussed at future meetings . . . subsequently the policy concerning cervical cancer screening was outlined.

The growing number of elderly patients needing community co-operation and help.

In conclusion it must be pointed out that two major questions remain unanswered—how representative can such a group be; and, while the greater sympathy between representative patients and their doctors is undoubted, how far does this communion spread to all the patients?

Clinical Curio

Readers may be interested to know about a slightly unusual application of ketotifen (Zaditen, Sandos). I have been treating an unfortunate lady, aged 45 years, who suffers from allergic rhinitis. So severe was her disease that at one time she was having polypectomies at intervals of two to three weeks, and this was not controlled by topical steroids, disodium cromoglycate, antihistamines, or topical decongestant/antihistamine mixtures. She was thoroughly investigated by a consultant chest physician and an ENT surgeon, but their treatment was to no avail. Eventually she was partially controlled by doses of 5 mg a day of prednisolone over two years.

Working on the theory that blocking all her mast cells would be beneficial if she was suffering from asthma as well as other allergic conditions, I started her on treatment with ketotifen 1 mg twice daily. The result was so remarkable that I believe this drug to be worthy of further consideration. In about six weeks her polyps disappeared completely, and her nose reverted to normal. The mucosa appeared only mildly congested, and of course the patient was delighted. Although the drug is not marketed with a licence for this condition I think it would be well worth bearing in mind for this purpose.—R G PINNOCK, general practitioner, Ashford, Kent.

Interviews for a practice

At one practice I was interviewed at the senior partner was a consultant gynaecologist; a most impressive personality, who used to ride with the foxhounds. When he advertised for a partner he had 300 applicants. I was shortlisted because he knew me. When I came to be interviewed he started by telling me off. "Why," he said, "don't you send a proper curriculum vitae?"

I said, "What do you mean?"

"You haven't told me what school you were at, whether you were a prefect, whether you played rugby for the school, or anything of importance. All you've got is useless medical details."

Partnerships would always tell you when you were interviewed exactly what you would have to do in the way of duties. You, as the interviewee, invariably had to challenge them as to what your pay was, and they looked down their noses at you and were absolutely scornful if you asked about off-duty and holidays. They'd say something like: "For God's sake, lad, we don't need to talk about things like that." They really were a very naughty bunch.

Only on one occasion was I ever asked about clinical practice. They took it for granted. One doctor, whom I liked a lot, did ask me about medicine, and if it hadn't been that I didn't like Mudtown I would have gone into partnership with him. He said to me: "How would you deal with acute asthma? Do you carry aminophylline in the bag?" And of course in those days sterilising 20-cc syringes was difficult, and doctors used to get the hospital to do it—at least I did. He was actually interested and asked. He was the only man who ever tested my clinical competence.—KEN DICKINSON, general practitioner, Birmingham.

We will be pleased to consider similar interesting stories about general practice.—Ed, BMJ.